

Upcoming 1999 Miniconferences

Most people with spinal cord disabilities are interested in learning more about their disability, secondary conditions and new treatment options. However, not everyone can get to Little Rock, even once a year, for an ASCC conference. Therefore, in 1999, two miniconferences have been scheduled to allow educational opportunities in other parts of the state.

The Northeast Arkansas miniconference will be in **Jonesboro** on

Friday, **June 18**, from 9:15 a.m. to 4:15 p.m. at HealthSouth Rehabilitation Hospital of Jonesboro. The Northwest Arkansas miniconference will be held in **Fayetteville** during **September**. The time and location for the Fayetteville miniconference have not yet been determined, but more details will be in the July *Spinal Courier*.

Each miniconference will include topics such as urological issues, spasticity, recreational options, pain management and work

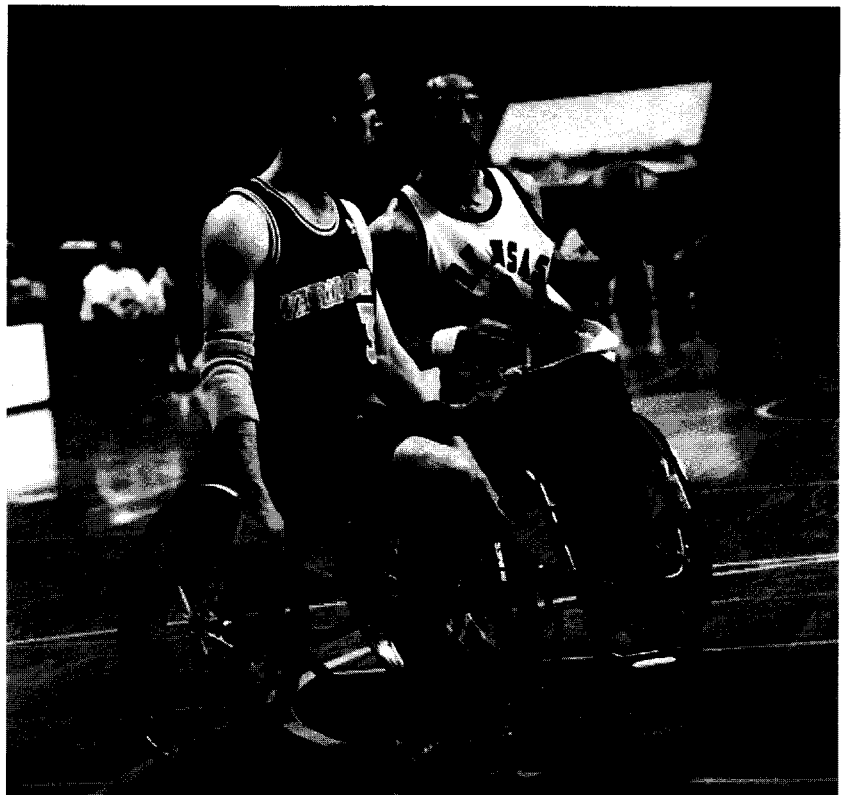
incentives. Also, each miniconference will include opportunities to see new equipment and medical supplies.

All ASCC clients and health care providers in these regions will receive brochures and registration forms providing full details about these miniconferences. If you do not live in Northwest or Northeast Arkansas and would like to be added to the miniconference mailing list, contact **Kristie Soto** at **800-459-1517** or **501-296-1792**. ☎

Time to Sign Up for Camp

The birds are singing, flowers are blooming and the weather is warming. That's right — Spring has come and that means it's time to get ready for our annual Spina Bifida camp. Every year, in cooperation with MedCamps of Arkansas, Inc. and Camp Aldersgate, Inc., ASCC sponsors a week long session of camping for children between the ages of six and sixteen at Camp Aldersgate in West Little Rock. This year camp will be held from **July 4 through July 9, 1999**.

For those of you who are unfamiliar with camp, here's the scoop. The MedCamps program features the traditional camping activities such as nature hikes, outdoor cooking, swimming, fishing, drama, music and arts and crafts that have been adapted so that each camper can participate to his or her fullest ability. All of the cabins,
Continued on page 3 - see "Spina Bifida Camp"



Arkansas Rollin' Razorback **Tim Kazee** (right) played in the '99 Final Four NWBT March 25-28 in Chicago. See 1999 NWBT Final Four on page 7. Photo courtesy of Curt Beamer, Sports and Spokes.

SPINAL COURIER

Published quarterly by
Arkansas Spinal Cord Commission

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Visit our website at:
www.state.ar.us/ascc
or e-mail us at:
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With Thanks

ASCC accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 800-459-1517 / TDD 501-296-1794**, or send your donation to:

AR Spinal Cord Commission
1501 North University, Suite 470
Little Rock, AR 72207

Donations this quarter from:

In Memory of Maurice Smith
Ann and Russell Patton II
Marie and Russell Patton III

In Memory of Marie Resh
Susan Sutterfield
Denise Thompson
Sandra Brown
Marie Boyce

Charles Gray
Betty Dodson
Marty Johnson

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

¿Habla Español?

Dear Editor:

ASCC is currently creating a database of Spanish translators and interpreters available throughout the state of Arkansas to use in its work with primarily Spanish speaking clients. To be included on the database, candidates must:

- have a good grasp of both English and Spanish (in both written and oral forms),
- be available for work during

- normal business hours, and
- be a resident of Arkansas.

For more information, contact me at :

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*Kristie Soto, VISTA Volunteer
Coordinator, McCluer Education
and Resource Center*

From the Director

It's a legislative year and folks have been hustling and bustling around at the Capitol since early January. Over two thousand bills have been filed. Can you imagine, as a legislator trying to read 2,000 bills (each is usually 3-5 pages long, some are as long as 100 pages!)? I can't. I have trouble trying to keep up with the ones I think relate to folks with spinal cord disabilities and our Commission. The good news is that the bill for the funding for ASCC passed and was signed by the Governor last month! The bad news (in my eyes, at least), is that the primary seat belt law (which would have put teeth in enforcing seat belt use) failed in the House of Representatives. That's further than it got in 1997, so maybe in two years (after 100 more SCIs and deaths) it will pass.

There's other interesting legislation being considered. A "wheelchair lemon law" that would make manufacturers accountable if a new wheelchair doesn't ever work right (a group of guys with SCIs in Hot Springs convinced Senator Canada that was needed). A "Medicaid Buy In" would allow low income working individuals with disabilities to purchase their Medicaid insurance, even after they go to work. A proposal to fund more independent living centers around the state. And, a much needed reform to the handicapped parking laws to put stiffer fines on those who misuse handicapped parking spaces.

By the time you read this, the last Arkansas legislative session of this century will be over. The decisions will be made on these bills and others. Will all the good and needed bills pass? Probably not! Will all the services we need get fully funded? Not likely there either. But, we will see some positive changes, some additional services, and maybe a few programs will go by the wayside. The folks we send to the Senate and House have a huge responsibility to carry out in less than 100 days every two years. We have a responsibility as citizens to let them know what's important to us.

It's never too early to start planning for 2001!

Cheryl L. Vines

Wheelchair Buyer Beware !

As you know, insurance companies, Medicare and Medicaid will pay for durable medical equipment (DME). Often, they will only purchase a wheelchair every five years, unless there is a significant need for a change (for example, amputation of a limb which changes the seating).

Recently we have been bombarded with TV and magazine advertising that encourages us to call and get a "new" chair at no cost. Sounds good, doesn't it? Some of you have already found out that there **are problems**. If you call to order a chair, they will send someone to measure you for the chair. This person very likely will **not** have the medical training to determine which particular chair best meets **your needs**. He will sell you a wheelchair that your insurance will approve. Your comfort and seating position involve a lot more than the size of the seat and back. Not only could the wrong chair be uncomfortable — it could cause pressure sores or other problems.

In a proper wheelchair evaluation, a person trained to look at every aspect of positioning will give you

the opportunity to try out different types of chairs. The therapist/evaluator will observe your seating posture, your comfort and the way you are able to move the chair.

If you feel you need a new wheelchair, call your ASCC Case Manager to get information on how to select a chair. As a consumer, you have some choices, but make sure you get all of the answers to make a good decision.

A provider who supplies you with a wheelchair should be able to make adjustments and repairs to the chair. If you purchase a chair through a company on TV, you may find that the company is in another state. Local companies are required to make repairs on Medicaid/Medicare chairs, but at busy times they, understandably, must first take care of the customers who purchased from them.

If you are using a wheelchair that has been loaned to you from ASCC or a local company and you decide to order a chair through a TV advertisement or a company who is out of state, please call your ASCC Case Manager or the local

company and ask that the loaner chair be picked up. Do **not** let the person delivering the new chair pick up the loaned wheelchair — the company who loaned the chair is usually not able to find it afterwards.

Keep these questions in mind when you look for a wheelchair:

- What will I do if the chair does not meet my needs?
- What are the qualifications of the person writing the prescription?
- Will I be able to try the chair before I order it?
- What number am I to call if I have problems with the chair?
- Will I be charged for repairs?
- Who will do the repairs?

Most DME salespeople are caring and honest, but there are unscrupulous salesmen who are eager to access Medicaid and Medicare funds. While all companies must charge enough to make a living, the **main objective is for you to get the appropriate equipment.** &

Spina Bifida Camp

Continued from page 1

dining hall, health care center and activity buildings are air conditioned and fully accessible. In addition, from the time camp starts on Sunday afternoon until camp ends on Friday morning, the campers are under one-to-one supervision with trained counselors and volunteers.

This really is a time of growth and learning for all of the campers while they spend a week full of fun-filled activities. Applications and brochures will be sent out in April and acceptance will be based on a first-come, first-served basis so be sure to send yours in as soon as possible. &

1999 Arkansas TRIO Hall of Fame



Paul Kidder of Malvern, AR, has been selected Ouachita Technical College's outstanding TRIO participant for induction into the 1999 Arkansas TRIO Hall of Fame. Selection is based on the individual's grade point average, community service, extracurricular activities and perseverance in overcoming life challenges. He was honored at a banquet and induction ceremony on February 20, 1999, at Arkansas State University.

Congratulations, Paul, on your achievement and recognition!

New Regional Office Provides Services for those with MS

The Multiple Sclerosis Association of America (MSAA) has good news for everyone with MS! They have opened a new Mid-South Regional Office in Little Rock which will serve Arkansas, Oklahoma, Texas, Louisiana, Missouri, Mississippi and Tennessee.

MSAA will provide a variety of free services, including:

- Free loan of therapeutic equipment
- Free patient information and newsletter
- No cost diagnostic MRI scans for the financially challenged
- Free cooling therapy, both at their office and through their in-home loan program
- Toll-free hotline for counseling and information
- Free MS library service
- Plus, many more support and education programs

The first program in place is the free cooling clinic. They have a

NES lab cooling unit that MSAA and NASA adapted for patient use. This very advanced piece of equipment will allow therapeutic cooling for up to six persons at once.

MSAA Mid-South is beginning a series of support group meetings. The first meeting for the Central Arkansas area will be held **Tuesday, May 25 at 6:00 p.m.** at the Mid-South Regional Office in Little Rock. Anyone interested in attending is encouraged to call.

Adam Roberts and Judith Harper-Bennie will be staffing the office. They have been working with multiple sclerosis for over five years. Their expertise includes clinical research, patient services and a long list of education programs.

MSAA Mid-South's grand opening will be held in early May and everyone is invited to drop by. Call **877-MS-SOUTH** or **501-565-4722** for more information. ☺

New Guideline for Treating Fatigue in Multiple Sclerosis

A new clinical practice guideline on treating fatigue in individuals with multiple sclerosis (MS) has been published by the Paralyzed Veterans of America (PVA). It is also available on the PVA website at www.pva.org.

Titled, *Fatigue and Multiple Sclerosis: Evidence-Based Management Strategies for Fatigue in Multiple Sclerosis*, this guideline is intended to be used by health-care professionals when making clinical decisions regarding the treatment of fatigue in individuals with MS. The guideline offers recommendations on assessment, diagnosis and treatment of fatigue associated with MS. It also provides

information on environmental and social factors, social support systems, consumer and family education and evaluation and modification of treatment plans.

"Fatigue is now recognized as the most common symptom of MS," stated Homer S. Townsend, Jr., PVA National President. "Not only does fatigue have an impact on impairment and disability, it is related to a patient's sense of control over the illness and overall mental health," he said.

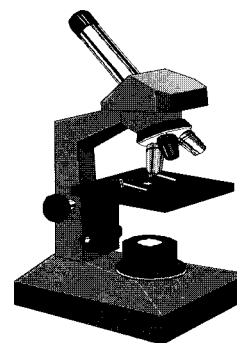
Health-care professionals may order a free copy by calling the PVA Distribution Center toll-free at **888-860-7244**. ☺

Virus Linked to MS

Researchers at the Institute for Viral Pathogenesis examined blood and lymph nodes from multiple sclerosis (MS) patients and found evidence of a single, active virus. The same virus was detected in brain tissue where nerve fibers were being destroyed.

Researchers have identified the virus as human herpes virus-6, the sixth member of the herpes virus family, which was discovered in 1987. HHV-6 is known to be present in 90 percent of the American adult population as a result of infection during the first few years of life. HHV-6 has been shown to cause roseola, a common childhood illness, and encephalitis. HHV-6 is divided into variant A

(less common and appears to be acquired by adults) and variant B. This variant infects most of the population, and it is acquired in childhood. Variant B



can exist in an inactive state until reawakened in adulthood. Researchers have long suspected that a slow acting virus triggers the onset of MS.

The presence of HHV-6 can be identified with a blood test to show when the virus turns active. There are two anti-viral drugs (Cytovene and Foscavir) used to treat HHV-6.

For more information, call Herpes Virus Diagnostics, Inc. at **414-529-3780**, or check out their website at www.hhv6.com.

-- Multiple Sclerosis Association of America

Reprinted from *The Allsup Alternative*, January/February 1999. ☺

Intrathecal Baclofen to Manage Spasticity

Tom Kiser, M.D., ASCC Medical Director

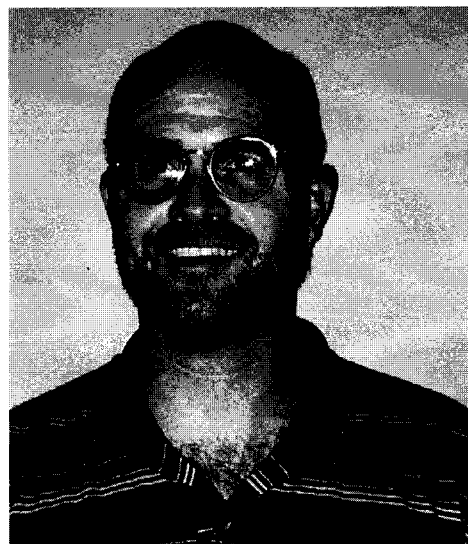
In this article I will discuss a relatively new therapy: Intrathecal Baclofen (ITB). Intrathecal (*intra* = *within* & *thecal* = *the dura mater*) means that the Baclofen is placed in the cerebrospinal fluid, the fluid that surrounds the spinal cord and the brain. The medication, Baclofen, is placed into the cerebrospinal fluid by a tube that is tunneled under the skin and placed through the outside sheath of the spinal cord, the dura mater. The Baclofen is then pushed through the tube into the cerebrospinal fluid via a pump. The pump is placed under the skin of the abdomen and powered by a battery. The pump must be refilled every 30 to 90 days in a doctor's office and may be reprogrammed to deliver the medication at different rates and at different times of the day. The battery lasts for about 5 years and then needs to be replaced, but a rechargeable battery is being investigated.

Baclofen can be taken orally and is usually very effective in decreasing spasticity. However, the side effect of sleepiness is often very limiting, and then other medication must be added or tried. When oral medication does not adequately control spasticity, the individual must either learn to live with the spasticity and the medication's side effects or try more aggressive therapy options. Surgical procedures that cut nerves or disrupt spinal cord pathways can be tried, but the results are not reversible. The advantage of ITB is that the dose is adjustable. So, if your tone is needed to stand or transfer, the medication can be reduced during the time of day when you need the increased tone. If your spasticity keeps you from sleeping, it can be increased during the hours of sleep. The concentration of Baclofen can

also be increased with little or no side effects noted by the patient.

If you feel that ITB could possibly help you, discuss it with your doctor. A good trial of oral medication should be used first with Baclofen, Tizanidine, and/or Dantrium. The medication can be used either alone or in combination and must reach an adequate dose. If the oral medication does not help or the side effects are not tolerable then you may be a candidate for ITB. A thorough assessment by a specialist in spasticity should be scheduled. If he/she feels you might benefit from ITB, an ITB screening trial will be scheduled. The ITB screening trial presently is conducted as an inpatient. You are admitted to the hospital and a lumbar puncture is conducted and a small dose of Baclofen is injected into the cerebrospinal fluid via needle in your low back. If you have a marked reduction in your spasticity and spasms you are a candidate for ITB. If you do not respond, the trial can be repeated two more times over the next two days with increasing doses of injectable Baclofen. After the trial, you and your doctor will discuss the results and decide whether or not ITB will benefit you.

If the trial is a success and you elect to have an ITB pump implanted, a surgical date will be scheduled. The surgical procedure takes about one hour. You can usually be discharged to home in two to three days after the procedure. The dose will be slowly increased over the next couple of months until the desired effect is reached. Your oral medication will be slowly tapered over the same time frame. The reduction in your spasticity will be gradual and you will not immedi-



ately feel the same reduction of spasticity as during the trial dose. There is no guarantee that ITB will improve your ability to function more independently or transfer better, but if you responded in the trial there is an excellent chance that it will reduce your spasticity. You may need more rehabilitation as an outpatient or inpatient to better manage yourself and adjust to the difference in tone and spasticity after the pump is implanted.

ITB is one more method to help you manage your spasticity and should only be attempted if oral medication does not work for you. If you have further questions concerning ITB, contact ASCC and we will send you more information. ☺

ENTERGY's Priority Services

Entergy offers a "Priority Service" for return of electric power in case of a power outage. To receive this service you will need to call your local Entergy office and tell them you need the priority service and the name and address of your doctor. A medical report form will be mailed to your doctor to be completed and returned to Entergy. Entergy will then evaluate your eligibility for a priority electric service return. ☺

Russellville Grand Prize Winner of Community Awards Competition

Seven cities and three counties are the recipients of cash prizes in the 1999 \$30,000 National Organization on Disability/United Parcel Service Community Awards Competition. The competition recognizes outstanding local programs and actions that expand the participation of citizens with disabilities in the life of the community.

Russellville, AR, was named the \$10,000 Grand Prize winner. Russellville won for the positive way the city came together to implement the Americans with Disabilities Act (ADA). The

comprehensive program includes advising local government, businesses and educational institutions, educating the community about disability issues and involving people with all disabilities.

With virtually no funding, the River Valley Accessibility Council of Russellville partnered with community leaders to move their attitudes from "have to do" to "want to do." Russellville was transformed from severe noncompliance of the ADA to a city with widespread compliance. According to River Valley Accessibility

Council Chair of the Board Sydney Case, the transformation occurred because of "people who are not afraid to dream, and then back those dreams up with their own blood, sweat and tears." What resulted was increased participation of people with disabilities in community life through improved accessibility and increased job opportunities.

Congratulations to the City of Russellville, its citizens and the River Valley Accessibility Council for earning this national award and recognition! &

Don't Be Afraid to Dream

by Shannon Tallent

I am 24 years old and have spina bifida. When I was born, I was not supposed to be able to walk, talk, sit up on my own or even think of caring for myself. In fact, my parents were told I would live life as a vegetable. My life has consisted of many trials and heartaches and, if I remember correctly, 36 surgeries. There have been many obstacles to overcome, but through faith and belief in God, I have either been able to overcome them or have been given the grace to bear the outcome.

While in high school I was diagnosed with renal failure at age 16. Not only was I being followed by the Spina Bifida Clinic, but I had the great fortune of meeting Dr. Wells and the staff at the Nephrology Clinic at Arkansas Children's Hospital (ACH) as well. The love, attention and care my family and I have received at ACH has been superb! The knowledge and communication skills of all the doctors, nurses and other staff is exceptional.

At age 20 I was having trouble with what I thought was allergies. It turned out to be just one allergy — latex. For years I'd wanted to become a health care professional and just as I was beginning my education this came up!

In 1995, I received my license as an Emergency Medical Technician (EMT). I applied with the local ambulance service and was hired as a dispatcher (this was not the position I desired!). I had spent hard earned money and a lot of time getting my certificate and I wanted to work on an ambulance. To convince the company I could do the job, I had different doctors examine me. They all had the same opinion — if I made it through EMT school then there is no reason why I shouldn't be able to do the job physically. But the company thought I was too much of a liability. I knew what I was capable of and had the skills for the job. Finally, I was given the chance to prove I could do the job I was trained for.



After working as an EMT, I resigned from the ambulance company in July 1997 in order to enter LPN school at Cossatot Technical College in DeQueen, Arkansas. I soon realized I wanted to specialize in pediatrics and work with children who are experiencing some of the same trials I had been through. Unfortunately, I did not pass my state boards the first time and am waiting to take them again. I have not yet given up.

My life has been packed full of blessings and achievements. I believe in myself and have people who believe in me. I want to let
Continued on page 7 - see "Dream"

Congratulations, Coach Garner

Doug Garner, coach of the Junior Rollin' Razorbacks, was recently selected President of the National Wheelchair Basketball Association's Youth Division Executive Committee. Coach Garner has been involved in wheelchair sports for several years. In 1994, he developed a youth program for Arkansas athletes with disabilities.

A number of his athletes hold national records in track and field. In only his second year, he coached the Junior Rollin' Razorbacks to a national championship after placing fifth the year before. In addition to sports, Coach Garner's athletes have also received academic awards for their outstanding accomplishments in the classroom.

Coach Garner, your youth program has been a success in Arkansas. Congratulations and good luck in your new role!

Dream

Continued from 6

other people know it can happen to them — just believe it, work hard, set goals and don't be afraid to dream. You are a special person. You can be an active member of society if you so choose. There is a place in life for you.

Once again, thank you for your publication and the opportunity it gives me to learn of new developments and the life of other people with disabilities. ♪

Junior Rollin' Razorbacks 8 1/2 Foot Team Champs

Birmingham, Alabama was the site of the first annual 8 1/2 Foot Wheelchair Basketball Championship on February 20-21, 1999. The 8 1/2 Foot Division was created to allow athletes 12 years old and under to compete in wheelchair basketball played on 8 1/2 foot basketball goals. Six teams entered the tournament, including the Arkansas Junior Rollin' Razorbacks.

The Arkansas Junior Rollin' Razorbacks played and won five games against Charlotte, Super Sports Alabama, Lakeshore Birmingham, Tulsa, and California on Saturday,

February 20th. The Razorbacks advanced to the championship game on Sunday where they met St. Louis in a very close and exciting game. The Razorbacks came away as Champions, winning by a score of 28-26. At the awards ceremony following the game, **Tyler Garner** was named the tournament's most valuable player, averaging 20 points per game.

Congratulations to the Arkansas Junior Rollin' Razorbacks 8 1/2 foot team and to MVP Tyler Garner! ♪

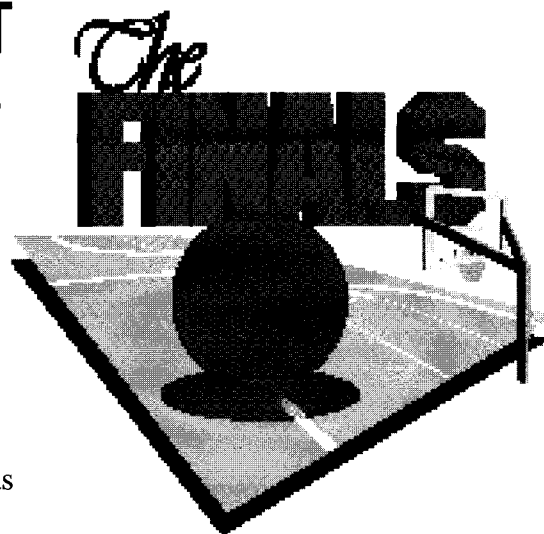
1999 NWBT Final Four Results

The Arkansas Rollin' Razorbacks took second in the 1999 National Wheelchair Basketball Tournament (NWBT) Final Four March 25-28 in Chicago, IL. During their semifinal game, Arkansas showed they were the team to beat and eased by the University of Wisconsin at Whitewater 73-53. The Championship game pitted Arkansas against the Dallas Wheelchair Mavericks, who had blown by the University of Illinois 65-46 in the semifinals.

Dallas started off quick and scored eight unanswered points before Arkansas turned up the defense and **Dave Kiley** led an Arkansas comeback, tying the score at 15 with 10 minutes remaining in the first half. **Tim Kazee** hit a 20 footer from the left baseline with

three seconds left, making the score 40-33 at the half, Dallas on top. By game's end Arkansas fell short to Dallas 78-60, making 1999 the third year the Dallas Mavericks have won the Championship title.

At the awards ceremony Rollin' Razorbackers **Dave Kiley**, **Darren Schenebeck** and **Jeff Glasbrenner** each received All-Tournament Team awards for their play for the weekend. ♪



McCluer Resource Center's Newest Items

The McCluer Education and Resource Center on Spinal Cord Injury has added a number of new items to its collection. If you are interested in checking out any of the resources, please call the Resource Center at **501-296-1792** or **800-459-1517** Monday-Friday (8:00 am-4:30 pm). Some of the new additions include:

- **Prostate Health: What Every Man Needs to Know** (audio-cassette).
- **Wheelchair Wijit News Story** is a video of a television report about the Wijit, a driving and braking system for manual wheelchairs. The Wijit uses a ratchet action to reduce shoulder strain as well as reducing the physical strength required to operate a manual wheelchair.

- **Acupressure's Potent Points** by Michael Gach describes the techniques and various uses of acupressure to relieve pain, stress and illness.
- **Spinal Network III**, edited by Barry Corbet, contains articles covering sports, social concerns, sexuality and medical aspects of spinal cord injury.
- **Entryways: Creating Attractive, Inexpensive No-Step Entrances to Houses** by Eleanor Smith.
- **SPINAbilities: A Young Person's Guide to Spina Bifida** by Marlene Lutkenhoff and Sonya Oppenheimer uses a straightforward approach to discuss such important issues as: relationship issues; healthy practices; exercise; career planning; and skin,

bladder and bowel care.

- **Gynecological Considerations in Treating Women with Physical Disabilities** by the Center on Research on Women with Disabilities contains information on abuse, women's health, and the ADA and health care providers. Has an accompanying video detailing alternative methods for gynecological exams for women with spinal cord disabilities.
- **Spinal Cord Injury: A Guide to Functional Outcomes in Physical Therapy Management** by the Rehabilitation Institute of Chicago.
- **Spinal Cord Injury: A Guide to Functional Outcomes in Occupational Therapy** by the Rehabilitation Institute of Chicago. ♿

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